The Diabetes Literacy Project: Strengthening diabetes self-management in Europe

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For the Diabetes Literacy Consortium

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The challenge of diabetes

- 387 million patients worldwide
  - 50% unaware that they have diabetes
- 4th cause of death in the EU
  - 300,000 deaths per year
- 5 to 15% of health care costs

- Impact of growing obesity and an ageing population
  - Increased number of people with diabetes
  - Increased health care costs related to diabetes

Source: Hossain et al. NEJM 2007 (million people)
The importance of self-management

- A key determinant of treatment outcome, as diabetes requires intensive self-care
- Enhancing self-management requires patient empowerment
- Questions regarding diabetes self-management education (DSME)
  - Which DSME programs are available (in the EU)?
  - What is the (cost)-effectiveness of different approaches?
    - Effectiveness of individual-based diabetes education programs has been proven, but not the cost-effectiveness
    - Group education, self-help support or IT supported education may be more (cost-)effective, but comparative studies of DSME approaches are scarce
  - What are the conditions for effectiveness?
    - e.g., characteristics of health care system, quality of implementation, …
  - What patient characteristics moderate the effectiveness?
    - Health literacy of Europeans: 10% inadequate and 35% limited HL
The Diabetes Literacy project

• A European project, funded by the EU through the 7th Framework Programme for Research
• A consortium of organizations from 6 EU Member States (B, D, IRL, NL, A, UK) + Israel, USA and Taiwan
  + DK and South Africa as collaborating partners
• Aims to provide empirical evidence to increase the effectiveness of self-management education for Type 2 diabetes in adults
Aims of the Diabetes Literacy project

• Perform a content analysis of national diabetes strategies (policies and programs) across the EU
• Assess the (cost-) effectiveness of different formats of diabetes self-management education
• Investigate
  – the mediating role of implementation fidelity on program effectiveness
  – the moderating role of the patients’ health literacy and of organizational characteristics (e.g., ease of access, multidisciplinary staff, patient monitoring system)
• Develop and pilot-test low literacy-appropriate ICT-materials for diabetes self-management education
Methodology

• Surveys among stakeholders
  – Description of the nature and quality of the national diabetes strategies via expert interviews
  – Inventory and description of existing DSME programs via Global Diabetes Survey + online wiki tool
  – Assessment of existing costing practices against best practice costing models

• Comparative clinical study
  – Compare effectiveness and cost-effectiveness of different types of DSM education programs
  – Investigate potential moderating or mediating factors for effectiveness (organisation, implementation, patient health literacy)

• Development and pilot testing of online educational materials for diabetes patients with low literacy
Main Findings

- A wide variety of DSME programs is available in Europe
  - Most programs use **group interventions** to empower patients to manage their diabetes
  - Peer-led support and IT-based programs are less common throughout Europe
  - Existing programs are **not equally distributed** in the population and do not reach all target groups
    - 40-60% of patients do not take part in diabetes education
  - **Patient participation** in planning and a participatory approach to program implementation are under-utilized

- Costs of diabetes self-management education
  - Costs **vary greatly** between countries and between programs within countries in the EU, as well as Taiwan and Israel
  - Compared to the overall costs of diabetes care and the treatment of complications, the **costs of DSME programs are low** (generally below € 20 per patient/hour)
Main Findings

• Effectiveness of DSME
  – Overall, DSME programs are **effective** in changing behavior and improving problem solving, healthy coping, and health related quality of life
  – There is no systematic significant difference in the effectiveness of different **formats** of programs (individual, group, self-help, IT-based)
  – Most of the intervention outcomes improved after the intervention, regardless of the provider’s adherence to the program guidelines
    For some outcomes, adapting the way in which the program is delivered (not the content) is associated with a greater improvement

• The potential of online support to self-management
  – A **good design** of web-based programs is more important than adding interactive and audiovisual materials elements
  – It is possible to develop web-based materials that are accessible to those with **lower health literacy** but also liked by those with higher literacy
Health Literacy and DSME

• Two roles of health literacy in DSME
  – An **outcome of DSME**: people who participate in DSME enhance their competence to successfully self-manage their disease
  – A **moderator** of effectiveness: people with low health literacy can be expected to benefit less from DSME

• Health literacy in the Diabetes Literacy study
  – As a patient characteristic (general HL, measured via HLS-EUQ6)
  – As an outcome of DSME (diabetes-specific HL, measured via DHL Scales)

• Findings
  – Significant main effects of HL on outcomes of DSME
  – No differences in effectiveness of DSME between people with high and low health literacy
Conclusions

- There is a window of opportunity in Europe to empower diabetes patients to successful self-manage their disease

- Rather than investing in the development of new DSME programs, existing programs should be made more available and accessible to patients, and more tailored to cultural and health literacy needs of the participant

- Intensifying and improving the training of providers of self-management education, including a greater focus on behavioural and psychological expertise, is essential to ensure the quality of DSME programs
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